

DOCUMENT RESUME

ED 321 445

EC 231 565

AUTHOR Condry, Sandra
TITLE Families of Children with Technology Support.
Annotated Bibliography. Report AB-1.
INSTITUTION Kansas Univ., Lawrence. Beach Center on Families and
Disability.
SPONS AGENCY National Inst. on Disability and Rehabilitation
Research (ED/OSERS), Washington, DC.
PUB DATE 89
NOTE 21p.
AVAILABLE FROM Assistant Director, Beach Center on Families and
Disability, 4138 Haworth Hall, Lawrence, KS 66045
(\$3.00).
PUB TYPE Reference Materials - Bibliographies (131)
EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Annotated Bibliographies; *Assistive Devices (for
Disabled); Children; *Physical Disabilities;
*Technology
IDENTIFIERS *Technology Dependence; *Ventilator Dependence

ABSTRACT

The annotated bibliography provides bibliographic information and non-evaluative abstracts of about 50 reports, books, journal articles, etc., concerned with disabled children who require technology support. Citations are listed alphabetically by author and were published from 1978 to 1989. (DB)

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Annotated Bibliography:

Families of children with
technology support

Sandra Condry, Ph.D

1989

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Families of Children With Technology Support: An Annotated Bibliography

Report AB-1

Sandra Condry, Ph.D.

1989

This annotated bibliography is the first of a number of bibliographies to be produced by the Beach Center at The University of Kansas. Although this is an in-depth look at the literature, it may not include all of the relevant sources.

The Beach Center on Families and Disability, a rehabilitation research and training center at The University of Kansas, is funded by the National Institute of Disability and Rehabilitation Research, United States Department of Education, and the University to conduct research on families with members who have disabilities. A major focus of the Center's research is the families of children who are supported by technology.



Beach Center on
Families and Disability

The University of Kansas
Bureau of Child Research
4138 Haworth Hall
Lawrence, Kansas 66045

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Annotated Bibliography

Aday, L. A., Aitken, M. J., & Wegener, D. H. (1988). Pediatric home care: Results of a national evaluation of programs for ventilator assisted children. Chicago, Ill: Pluribus Press, Inc., and the Center for Health Administration Studies, University of Chicago.

This book presents the findings of a comprehensive evaluation of three SPRANS-supported demonstration projects which were to develop regionalized, comprehensive, coordinated systems of care for children who are ventilator assisted and their families. It presents quantitative and qualitative data from the perspectives of the system, the program and the families. Chapters address the evaluation design and methodology, descriptions of the environments of the three states as well as the programs that were implemented. The book provides qualitative evaluation data of the programs, from both internal and external sources as well as considerable demographic data collected on about 70% of the identified children and families in the three states. Four questionnaires, based on Stein & Jessup (1984), and open-ended questions were administered to the primary caregiver (almost always the mother) as outcome measures of the impact of home care on the family and on the child. A comparison of the relative costs of home care and institutional care was made on a subset of the sample. The authors concluded that home care programs reduced the costs of care for a child who is ventilator assisted, mainly by substituting parental for professional nursing services in the home. However, families with less nursing care reported greater levels of caregiver stress. Implications for similar programs, for families, for policy, and for research are discussed.

Aday, L. A., & Wegener, D. H. (1988). Home care for ventilator-assisted children: Implications for the children, their families, and health policy. Children's Health Care, 17 (2), 112-120.

This article presents some of the data of the Aday, Aitken, & Wegener (1988) national evaluation study of home care programs for children who are ventilator-assisted; its focus is on the impact on the children and their families. It provides a neat summary of the research design and methodology and then presents the major findings of the caregiver interviews and discusses some of the policy implications. Quotes from interviews are included. There is discussion of family adjustments to home care; the pros and cons of full-time nursing care; the need of the families and children for social and psychological support; the changing needs over time; and the financial burdens of home care that cause measurable stress to the families.

Astbury, J., Orgill, A. A., Bajuk, B., & Yu, V. Y. H. (1985). Neonatal and neurodevelopmental significance of behaviour in very low birth weight children. Early Human Development, 11, 113-121.

Thirty-four percent of 213 inborn, long term survivors with a birth weight of less than 1500 grams showed characteristics of Attention Deficit Disorder (ADD) during psychological testing at two years of age corrected for prematurity. Children with ADD differed from those with normal behavior on a number of neonatal variables; these neonatal variables correctly classified 69% of children into their actual behavior group at two years. Children with ADD had a significantly lower mental score on the Bayley Scales of Infant Development and were found on pediatric/neurological examination at two years to have a significantly smaller head circumference, more tone disorders, poorer visual tracking and visual motor coordination, poorer gross and fine motor coordination, and significantly more minor physical and neurological disabilities than children with normal behavior. The behavior of very low birth weight infants during psychological testing at two years is a potent indicator of past neonatal experience and current neurodevelopmental status.

Batshaw, M. L., & Perret, Y. M. (1981). Children with handicaps: A medical primer. Baltimore, MD: Paul H. Brookes Publishing Co.

This is a basic text for special education and other child specialists. It discusses genetic and prenatal diagnostic techniques used to detect abnormalities, prenatal development, and the birth process. The book also discusses organ systems of the body and the ways in which each can go wrong, with in-depth descriptions of various conditions causing disability. It also includes some case studies and raises emotional aspects and ethical questions.

Blacher, J. (1984). Sequential stages of parental adjustment to the birth of a child with handicaps: Fact or artifact? Mental Retardation, 22(2), 55-68.

The author argues that the concept of sequential stages of adjustment is a useful heuristic although the literature displays problems in definition of the stages, in descriptions of the rate parents proceed through the stages, and in applications of the model. He argues for collapsing the various taxonomies into three major groupings and for using changes in parents' reactions as the measure of movement from one stage to the next. The three stages are initial crisis responses (shock, denial, and disbelief); continuing feelings and responses (emotional disorganization); and adjustment or acceptance (emotional reorganization). Methodological problems and critical issues are discussed.

Bozynski, M. E. A., Nelson, M. N., Matalon, T. A. S., O'Donnell, K. J., Naughton, P. M., Ushanalini, V., Meier, W. A., & Ploughman, L. (1987). Prolonged mechanical ventilation and intracranial hemorrhage: Impact on developmental progress through 18 months in infants weighing 1,200 grams or less at birth. Pediatrics, 79 (5), 670-676.

This is a prospective, longitudinal study of the relative impact of intracranial hemorrhage, and prolonged mechanical ventilation on developmental progress during the first 18 months of life of infants weighing 1200 g. or less. A total of 159 surviving infants were divided into two groups: those with and without intracranial hemorrhage. These groups were subdivided into groups of infants receiving prolonged mechanical ventilation for (less than 21 days) and those ventilated for greater than 21 days. Analysis of variance found a main effect for prolonged mechanical ventilation on outcome as measured by the Bayley Mental Development Index and Bayley Psychomotor Development Index (PDI) at 4, 8, 12, and 18 months of age (corrected for prematurity). Regression analyses found prolonged mechanical ventilation to be the best predictor of Bayley indexes at all ages except four months of age, for which length of hospitalization was the best predictor of PDI. No main effect of intracranial hemorrhage was found, although motor performance of these infants declined with age.

Burr, B. H., Guyer, B., Todres, I. D., Abrahams, B., & Chiodo, T. (1983). Home care for children on respirators. The New England Journal of Medicine, 24, 1319-1323.

This is a report of a study of six families in Massachusetts who undertook home care of their children who were ventilator dependent. The report presents characteristics of the children and the families. Parents report beneficial effects on child and family as well as negative effects; they identify unmet needs. Cost analysis shows that the cost of home care is 50 to 95 % lower than hospital costs. Recommendations are made for the planning of home care. The financial problems families face are discussed as is progress in solving some of the problems.

Cannon, R. A., Byrne, W. J., Ament, M. E., Gates, B., O'Connor, M., & Fonkalsrud, E. W. (1980). Home parenteral nutrition in infants. The Journal of Pediatrics, 96 (6), 1098-1104.

This paper reports on eight infants studied over a two year period on effects of home total parenteral nutrition on growth and psychomotor development. Six of the eight infants displayed normal psychomotor development following discharge from hospital. Measures of weight, height, head circumference, and Gesell scales were taken. Metabolic and infectious complications are reported. There are two additional reports on children in the same program at earlier and later ages (Cannon et al., 1980; Ralston et al., 1984).

Chesler, M. A., & Barbarin, O. A. (1984). Difficulties of providing help in a crisis: Relationships between parents of children with cancer and their friends. Journal of Social Issues, 40 (4), 113-134.

This is part of a larger study of families with a child with cancer, this part presents qualitative research on the reciprocal effects of the helping relationship between parents and their friends and the difficulties adults encounter. Sensitivity is necessary for successful relationships, but it can also prevent parents from seeking help and friends from offering it. The study finds sex differences in seeking/accepting help and in offering help. The report recommends recognition of the important role friends can play and suggests ways to facilitate the involvement of friends in the family's support system.

Department of Health and Human Services (1988). Fostering home and community-based care for technology-dependent children: Report of the Task Force on Technology Dependent Children (HCFA Publication No. 88-02171). Washington, DC: U.S. Government Printing Office.

The purposes of the Task Force were to identify barriers that prevent the provision of appropriate care in a home or community setting for children who are technology supported and to recommend changes in the provision and financing of health care in order to provide home and community-based alternatives to institutionalization. The report provides definitions of key terms. Identified barriers included governmental and policy barriers, access barriers, absence of standards and quality assurance, lack of case management systems, unmet developmental and educational needs of the children, lack of family support and respite care services, focus efforts at prevention, and serious financing problems, both public and private. The report gives recommendations for each problem area.

Fischer, D. A., & Prentice, W. S. (1982). Feasibility of home care for certain respiratory-dependent restrictive or obstructive lung disease patients. Chest, 82 (6), 739-43.

This is an evaluation of a home care program for 29 adults who are ventilator dependent and who have permanent tracheostomies and no prior use of a respirator in the home. Subjects served as their own controls; data were presented on experiences prior to and after home care initiation. Results showed positive effects or at least stability on medical measures, increased independence and satisfaction, and decreased cost.

This study provides medical and economic data on adults who became technology-dependent during middle- or old-age.

Frates, R. C., Jr., Splaingard, M. L., Smith, E. O., & Harrison, G. M. (1985). Outcome of home mechanical ventilation in children. The Journal of Pediatrics, 106, 850-856.

This is a retrospective study of the outcome of home mechanical ventilation on 54 children with chronic respiratory insufficiency, ages four months to 18 years. Tracheostomies and positive pressure ventilation were used in 33 patients, and negative pressure ventilation in 21 patients. Nine patients were eventually weaned from the ventilator, including three quadriplegic patients in whom electrophrenic stimulation subsequently was used. Over 20 years of data, there were 17 deaths, including three from ventilator disconnection. Life table analysis showed 1-year survival to be 84%, and 5-year survival 65%. Home mechanical ventilation, with patients cared for by family and friends, cost less (average <\$1000/mo) than full-time home registered nurse or hospital care (which were identical, at \$16,000/mo). There was no significant difference in the number of deaths between patients cared for by registered nurses 24 hours a day and those cared for by family and friends. A conclusion was that home mechanical ventilation may be a reasonably safe and cost-effective alternative to prolonged hospitalization for the child who is ventilator-dependent.

Friedrich, W. N., Greenberg, M. T., & Crnic, K. (1983). A short-form of the Questionnaire on Resources and Stress. American Journal of Mental Deficiency, 88 (1), 41-48.

This article presents reliability and concurrent validity data on a short form of Holroyd's Questionnaire on Resources and Stress, which was designed to measure stress in families of children who have developmental or mental disabilities. The short form consists of 52 items, which factor analyze into: Parent and Family Problems, Pessimism, Child Characteristics, and Physical Incapacity. The Family Problems scale (with 20+ questions) may be useful as an assessment and evaluation measure for family intervention programs.

Gisel, E. G., & Patrick, J. (1988). Identification of children with cerebral palsy unable to maintain a normal nutritional state. The Lancet, 6(1), 283-6.

This study, compares seven children aged 2-16 with severe cerebral palsy and growth failure with children of the same weight, with respect to their eating efficiency. Children with cerebral palsy took 2-12 times longer to chew and swallow a standard amount of pureed food and 1-15 times longer to chew and swallow solid food than did their weight-controls. Even long meal times did not compensate for the severity of these children's feeding impairment. This measurement of feeding efficiency can provide a basis for early identification of children who cannot be adequately nourished without ancillary feeding by nasogastric tube or by enterostomy (a permanent opening into the intestine).

Goldberg, A. L., Faure, E. A. M., Vaughn, C. J., Snarski, R., & Seleny, F. L. (1984). Home care for life-supported persons: An approach to program development. Journal of Pediatrics, 104 (5), 785-95.

This paper describes a program for home care of children who are ventilator-dependent that had been in operation for five years at the time of report. It lays out the various aspects of planning and implementation and makes note of the problems encountered as well as presenting data on the 16 children released to home care through the program. Outcome data includes time since discharge, hours of professional nursing care per day, qualitative developmental statements, and claims of substantial cost savings. The paper makes recommendations for setting up other such regional programs.

This is not an experimental study of the children; there is no control group, nor any quantitative data on pre-release status or developmental gains.

Hobbs, N., & Perrin, J. M. (Eds.) (1985). Issues in the care of children with chronic illness. San Francisco: Jossey-Bass Publishers.

This is a lengthy book presented as a sourcebook on problems, services, and policies about children with chronic illness and their families. It serves this role well. The book covers seven topics; the several chapters within each topic were commissioned from leaders in their respective fields. The book introduces basic concepts and explores the impact of chronic illness on children and families. Also, the book presents the epidemiology and demography of childhood chronic illness and then individually reviews of cause, treatment and outcome of eleven groups of severe chronic conditions. In addition, the book describes populations at special risk as well as discussing the activities of professionals. The book also discusses the education of children with chronic illness and makes policy recommendations.

Hobbs, N., Perrin, J. M., & Ireys, H. T. (1985). Chronically ill children and their families. San Francisco: Jossey-Bass Publishers.

This book is a companion to the Hobbs and Perrin (1985) book and presents the findings from the Vanderbilt Study of public policies affecting children with chronic illness and their families. Its purposes are to examine the strengths and weaknesses in current patterns of care, financing, professional training and research as well as to analyze and recommend policy options. The book gives an overview of chronic childhood illness and of current patterns of care as well as exploring effects of chronic illness on the child, the family, and the community. The book also investigates the educational system, the health care system, and the systems for financing care as well as discussing research needs and needs for the training of health care professionals. It also presents policy recommendations and choices, based on discussions of values and principles. The book is a scholarly and provocative presentation of current issues.

Intagliata J., & Doyle, N. (1984). Enhancing social support for parents of developmentally disabled children: Training in interpersonal problem solving skills. Mental Retardation, (Feb.), 4-10.

The authors note that parents of children with developmental disabilities, in order to benefit from social support must be interpersonally competent, while most interventions focus on the problems they have with their child with a disability. This is a report on a pilot study to assess the degree to which the interpersonal problem solving skills of parents of children with developmental disabilities may in fact be deficient and to assess their responsiveness to a training program designed to enhance their interpersonal problem solving competence. Four families participated in a two-hour training session once a week for 10 weeks. Training was highly structured, making extensive use of role play and regular homework assignments. Participants were taught a five-step process for dealing with interpersonal problems. A Means-ends Problem Solving Procedure was administered as the pre-post test measure. Participants showed improvement in their performance on interpersonal and intrapersonal test problems, but not on their already high performance on the problem concerning a child with a disability. Over time, the parents agreed that they did have some significant problems with managing conflicts with other individuals in their lives. Follow-up three months later was positive.

Kirkhart, K. A., Steele, N. F., Pomeroy, M., Anguzza, R., French, W., & Gates, A. J. (1988). Louisiana's Ventilator Assisted Care Program: Case management services to link tertiary with community-based care. Children's Health Care, 17 (2), 106-111.

This article describes the case management services of the Louisiana VACP, which has two major components -- individualized planning and services coordination. An overview of the accomplishments of the program is provided. Consumer views of the case management services, based on open-ended telephone interviews of five families, are presented. Parents report the major problems they face caring for their children at home (fear for their child's well-being, problems with supplies, sense of isolation and neglect of siblings, financial deprivation), as well as unmet needs (respite care, counseling for child and family), and what they need from case management (24-hour-accessibility, a willingness to listen and assist, and a case manager who will meet their needs when they are needed). Three case examples are provided. Difficulties faced by case managers are discussed.

Kirkhart, K. A. & Gates, A. J. (1988). Home care of children assisted by high-tech medical supports. In H. M. Wallace, G. Ryan, & A. C. Oglesby (Eds.), Maternal and child health practices (3rd ed.), (pp. 673-681). Oakland, CA: Third Party Publishing Company.

This chapter provides an overview of the issues surrounding home care of children who are technology-supported and their families. It includes a brief

description of the work of the two national task forces, the home care plans that are needed and sources, the services a family needs and how these may be funded. The chapter also reports results of the few evaluations of home care and the major unmet need: for successful provision of home care.

Kleinberg, S. B. (1982). Educating the chronically ill child. Rockville, Maryland: An Aspen Publication.

This is an informed and readable overview of chronic illness, its possible effects on the child and the family, and advice to educators on their roles. The author takes an Ericksonian point of view in her discussion of the effects of chronic illness on the child -- she presents likely effects of illness in relationship to the tasks of each stage of development. Her discussion of the child's perspective is especially well done. Another section discusses family functioning. Several chapters describe the more common of the chronic childhood illnesses and a chapter on the dying child. The educator's role is included in all the discussions. Two final chapters which address the educator as team member and as advocate.

Kohrman, A. F., & Diamond, L. (1986). Institutional and professional attitudes: Dilemmas for the chronically ill child. Topics in Early Childhood Special Education, 5 (4), 82-91.

The authors make a strong argument for the need for changes in the way medical professionals view and deal with chronic illness. While the business of childhood for children with chronic illness is growth and development, the institutions which serve them often fail to allow development of an invested relationship that encourages independence. Social attitudes and institutional practices which cause problems for the child and the family are identified. The authors argue for a reorientation of values toward the promotion of the child's development which should include orientation toward interdisciplinary team work and home care.

Lange, B. J., Burroughs, B., Meadows, A. T., & Burkey, E. (1988). Home care involving methotrexate infusions for children with acute lymphoblastic leukemia. The Journal of Pediatrics, 112 (3), 492-495.

This is a report of one part of a collaborative study to provide chemotherapy infusions at home as opposed to hospital for children with acute lymphoblastic leukemia. The rationale for the study is given. It describes the characteristics of the program and some preliminary results, which are parent satisfaction, reduced costs, only minor problems. Possible advantages and disadvantages of home care are discussed.

Locker, D., Kaufert, J. M., & Kirk, B. (1987). The impact of life support technology upon psychosocial adaptation to the late effects of poliomyelitis. Birth Defects Original Article Series, 23 (4), 157-171.

The paper is an in-depth followup to an epidemiological survey of a representative sample of the ventilator-dependent survivors of the major Manitoba poliomyelitis epidemics of the 1950's. It documents the impact of changing respiratory-support technology upon individual adaptation, particularly to late, polio-related aging effects. Survivors were 8-35 years at polio onset; followup was performed 30-35 years later. All experienced at least a partial return to mechanical support, this time with a positive pressure ventilator rather than an iron lung, as their respirator status decreased. The respondents were accepting of this dependence if it maintained levels of functioning and enhanced the quality of life.

McKeever, P. (1983). Siblings of chronically ill children: A literature review with implications for research and practice. American Journal of Orthopsychiatry, 53 (2), 209-218.

This is a short literature review, somewhat dated, that presents arguments for expecting there to be effects on siblings as well as some of the findings on communication restriction within families about the child's illness, evidence on role shifts within the family, discussion of the shortage of resources for the healthy siblings, review of the siblings' responses to the child's illness and factors that appear to affect those responses such as SES, child's ordinal position, and characteristics of the disease. Implications for research and clinical intervention are given.

Miller, J. R., Colbert, A. P., & Schock, N.C. (1988) Ventilator use in progressive neuromuscular disease: Impact on patients and their families. Developmental Medicine and Child Neurology, 30, 200-207.

Duchenne muscular dystrophy is a progressive disease with an average life expectancy of 18.5 years. The most common cause of death is respiratory failure which is technically easy to ventilate. However, there is lack of consensus on whether patients and families should be given this option. This study explores patient and family decisions about extending life, documents stresses that develop after ventilation, determines factors that influence the quality of life, and identifies intervention strategies for health-care providers. Fifteen people were interviewed; none reported regretting the decision to accept ventilation, and no one who was offered the opportunity refused it.

Miller, B. F., & Keane, C. B. (1983). Encyclopedia and dictionary of medicine, nursing, and allied health, 3rd Ed. Philadelphia: W.B. Saunders Co.

As the title indicates, this book provides significantly more information than a dictionary but since it is only a single volume, it is not encyclopedic in its coverage of any term. This is a good sourcebook for the medically-underinformed reader.

Mughal, M., & Irving, M. (1986). Home parenteral nutrition in the United Kingdom and Ireland. The Lancet, August 16, 383-386.

This is a report on the 200 patients registered as receiving home parenteral nutrition in United Kingdom and Ireland. Most patients started treatment between ages of 10 and 40, many as result of Crohn's disease. Eighty five required treatment for less than one year. This study uses a 4-point scale on quality of life. It reports frequency of catheter-related problems and proportion of deaths by diagnosis and whether or not related to home parenteral nutrition (HPN). The report provides estimate of cost of HPN and argues it is a cost-effective treatment.

O'Connor, M. J., Ralston, C. W., & Ament, M. E. (1988). Intellectual and perceptual-motor performance of children receiving prolonged home total parenteral nutrition. Pediatrics, 81 (2), 231-236.

Twelve children receiving prolonged home total parenteral nutrition, ages 2-4 to 7-9, were tested for intellectual and perceptual-motor function. The results showed that all children functioned within normal range of intelligence, but the majority of children evidenced some deficits in perceptual-motor performance and this was particularly true of older children. Medical complications were related to nonverbal intelligence and to perceptual-motor functioning. Social class was related to verbal intelligence but not to perceptual-motor performance. There was some indication that older children were having more difficulty with attention tasks of the WISC-R; parent interviews supported this. At least some of the perceptual-motor problems may have been because of deficiencies in the nutrition solution; improvements have been made.

Office of Technology Assessment. (May, 1987). Technology-dependent children: Hospital v. home care -- A technical memorandum, (OTA-TM-H-38) Washington DC: U.S. Government Printing Office.

This memorandum provides a working definition of technology dependence and estimates the prevalence of technology dependence among American children (and describes the method of estimation). It presents trends in the population at risk of technology dependence and summarizes existing evidence on the effectiveness of home care and the components that may affect it. At the time, concrete evidence was lacking. The memorandum gives evidence regarding the costs of home versus hospital care and identifies general factors that tend to increase and decrease relative costs. The memorandum also discusses the extent and adequacy of private insurance

coverage and gives several reasons for the inadequacy. Investigation of the extent of public payment finds that Medicaid has made progress, although regulations require evidence of a cost saving which is difficult because Medicaid pays much less for hospital care than does private insurance. Crippled children's programs in the states likely have a significant role to play.

Office of Technology Assessment. (December, 1987). Neonatal intensive care for low birth weight infants: Costs and effectiveness. (Health Technology Case Study 38), (OTA-HCS-38.), Washington, DC: U.S. Government Printing Office.

This is a case study that reviews of the evidence on the effectiveness of neonatal intensive care for low birth weight infants. It provides an inventory of the neonatal intensive care units, with trends and costs. It discusses mortality and handicap rates, and the outlook for infants with respiratory distress syndrome, intraventricular hemorrhage and retinopathy of prematurity. The study reviews problems in financing as well as unequal mortality risks. It presents an analysis of lifetime economic implications for infants and society. A conclusion is that . . . "the rate of serious long-term disability increases with decreasing birth weight, but within each birth weight group, the proportion of NICU survivors who have serious handicaps has not changed significantly since the introduction of neonatal intensive care" (p. 5).

Palfrey, J. S., Walker, D. K., Butler, J. A., & Singer, J. D. (1989). Patterns of response in families of chronically disabled children: An assessment in five metropolitan school districts. American Journal of Orthopsychiatry, 59 (1), 94-104.

This is a substudy on the impact on families as part of a national study of childhood disability and special education. Interviews with parents of 1726 special education students yielded reports of stress that varied significantly by type of disability and by maternal education level; family involvement in the special education process also varied significantly by level of education. The report describes clinically important differences in family perceptions and coping mechanisms and the need for better child care provisions and highlights the involvement of low-income parents in the education process.

Pierce, P. M., Freedman, S. A., & Reiss, J. G. (1987). Prescribed Pediatric Extended Care (PPEC): A new link in the continuum. Children's Health Care, 16 (1), 55-59.

This article provides a description of a model program for children who are technology-supported, a case example and some cost comparisons. The Prescribed Pediatric Extended Care (PPEC) Center is a nonresidential, family-centered health care service prescribed by a physician for children who are medically and/or technologically dependent. As part of the continuum of care for children who are medically dependent, the PPEC center provides a triad of necessary services: day

medical care, developmental programming, and parent training. The PPEC Center provides a less restrictive alternative to hospitalization and reduces the isolation often experienced by the child who is home-bound and medically dependent.

Platzker, A. C. G. (1988). Fostering home and community-based care for technology-dependent children: Report of the Task Force on Technology Dependent Children (HCFA Publication No. 88-02171). Washington DC: U.S. Government Printing Office.

In response to Task Force questions and as representative of the Children's Hospital of Los Angeles, the author was strongly supportive of the home care movement. He cautioned that younger children, whose medical status can change rapidly, were especially in need of multidisciplinary teamwork. He argued for State and Federal regulations in several areas. In response to the Task Force question as to barriers to appropriate care in the homes of children who are technology dependent, Dr. Platzker discussed the unanticipated stresses and disruptions in the lives of family members. An important stressor for families with home nurse assistance is the set of problems caused by poorly trained nursing help, high turnover and unanticipated absences. He remarks that the parent-nurse relationship, which should be cooperative, too often becomes adversarial.

Pless, I. B., Satterwhite, B., & Van Vechten, D. (1978). Division, duplication and neglect: Patterns of care for children with chronic disorders. Child: Care, health and development, 4, 9-19.

The authors interviewed parents of 44 children with chronic arthropathies (usually juvenile rheumatoid arthritis) to determine their perceptions of how management responsibilities are shared between primary physicians and specialists. They asked questions on nine specific areas of care, as to which physician assumed major responsibility. Results showed a pattern whereby basic care is either divided or duplicated but with many of the supportive aspects of care neglected in a high proportion of families. This is common for children with chronic disorders. The authors concluded that there is fragmentation of the way care is most often provided. There is a need for a comprehensive, carefully monitored, and coordinated treatment plan to assist the children.

Powell, T. H., & Hecimovic, A. (1985). Baby Doe and the search for a quality life. Exceptional Children, 51 (4), 315-323.

The authors present a schema for investigating the quality of life issue and argue that six dimensions can describe the quality of a person's life. They present instances of scientific advances in each of these areas, implying that a present-day, severely compromised infant has a good chance of achieving a life worth living. There is a call to professionals to make this information known to life-and-death decision-makers.

Ralston, C. W., O'Connor, M. J., Ament, M., Berquist, W., & Parmelee, A. H., Jr., (1984). Somatic growth and developmental functioning in children receiving prolonged home total parenteral nutrition. The Journal of Pediatrics, 105 (5), 842-846.

This study reports on nine children studied longitudinally from infancy to three years of age. All were participants in a prolonged home total parenteral nutrition program at UCLA. Growth and psychomotor development were measured (including Gesell Scales and Stanford-Binet). Normalization of somatic growth occurred by two years in all children. Patterns of developmental performance are reported and discussed. The study provides some information on discharge planning to home.

SKIP of Maryland, Inc. & SKIP National. (1988). Families to families: An introduction to the home care experience. New York: SKIP.

This is a parent manual to assist families in achieving family-centered care at home for children who are technology supported. SKIP (Sick Kids Need Involved People) is a support and advocacy national organization for parents of children who are chronically ill. Chapters discuss common thoughts and feelings of families at significant times; dealing with the hospital; discharge planning (including some useful forms); common problems and tips for managing them; issues of community integration; resources for additional information (books and media material, and toll free numbers).

Sirvis, B. (1988). Students with special health care needs. Teaching Exceptional Children, 20 (4), 40-43.

This is an article about children with special health care needs (which includes children who are dependent on technology) which provides information and advice to teachers. The author discusses appropriate and least restrictive placements, with reasons that justify each particular placement. She gives advice to teachers on types of modifications that may be needed to educate these children in regular classrooms. She asserts that a regular classroom is the appropriate placement for the majority of students with special health care needs.

Stein, R. E. K., & Jessop, D. J. J. (1984). Does pediatric home care make a difference for children with chronic illness? Findings from the pediatric ambulatory care treatment study. Pediatrics, 73 (6), 845-53.

This is an experimental evaluation of an ambulatory care service for children with chronic illness, using pre-post-test design and stratified random assignment of children to experimental and control groups. Standardized measures were

administered to mothers. Positive effects of Pediatric Home Care were found on mother's satisfaction with medical care, psychological adjustment of the child, and perhaps on mother's psychiatric symptoms. These children were not technology dependent but were chronically ill. The sample was urban, predominantly poor and largely made up of minority group members.

Stein, R. E. K., Perrin, E. C., Pless, I. B., Gortmaker, S. L., Perrin, J. M., Walker, D. K., & Weitzman, M. (1987) Severity of illness: Concepts and measurements. The Lancet, (8574), 1506-1509.

The term "severity" is often used vaguely and inconsistently; it has been used in descriptions of the underlying biological defect, the amount of illness or disability caused by a condition, the condition's impact on quality of life, and the financial, social, or emotional burden imposed by the illness. Severity is not an absolute or universal concept, and the appropriate measure depends on the purpose. Three categories of proxy measures are physiological or morphological severity, functional severity and burden of illness. The authors advise using more than one measure whenever possible for maximum validity.

Tejani, A., Mahadevan, R., Dobias, B., Nangia, B. S., & Varma, P. N. (1979). Total parenteral nutrition of the neonate--a long-term followup. The Journal of Pediatrics, 94 (5), 803-805.

This is a retrospective study of 26 children at 4-1/2 to 7-1/2 years who had been given total parenteral nutrition shortly after birth for 2-43 days because of their inability to ingest orally sufficient caloric intake. Each child was matched with a control. For the six children who were not low birth weight, but received total parenteral nutrition immediately after birth, the mean IQ was average and not different from that of their controls. Of the 20 children who were low birth weight, seven (35%) at followup had IQ less than 90; this was significantly lower than that of their controls. This is the same per cent reported in studies of low birth weight children who did not receive total parenteral nutrition; it appears that neonatal intervention with TPN does not have significant effects on intellectual development. Of the seven low IQ children, most were also retarded growth.

Thomas, R. B. (1987). Methodological issues and problems in family health care research. Journal of Marriage and the Family, 49, 65-70.

This article discusses issues that arose when the author performed ethnographic research on seven families with children who were technology supported. It discusses three areas: questions about the appropriate selection of informants and data sources; the many factors that limit sample selection and thus the generalizability of the research results; and questions about the subject's ability to differentiate between research and therapeutic intervention.

Turnbull, K., & Bronicki, G. J. (1989). Children can teach other children. Teaching Exceptional Children, 21 (3), 64-65.

A heartening instance of informal support by peers of a child who is technology-supported. A disability-wise second-grader provided her healthy peers with an instructional videotape about caring for a child with mental retardation who received nutrition through a nasogastric tube. She also provided these peers with an opportunity to interact with the child. In a pre-post-test design, she found her peers reported they had learned how to take care of some of the child's special needs and also thought they would be comfortable taking care of these needs.

Walker, D. K. (1987). Chronically ill children in schools: Programmatic and policy directions for the future. Rheumatic Disease Clinics of North America, 13 (1), 113-120.

In this article the author lays out issues and concerns surrounding the provision of school services for children with chronic illness. There are many potential problems facing these children in the learning and psychosocial domains, and they may need a variety of special services, many of them medical. She presents the federal requirements for special education placement and services, and discusses where children with chronic illness fit, and notes that some children are excluded from receiving related services because they are not in need of special education. The cost of these "extra" services is a problem. She discusses the problems school health services have in coordinating across line units, the general lack of policies regarding nursing procedures for children with chronic illness, the need for and general lack of training for school personnel, and even the lack of school nurses in some districts. She recommends a list of key policy issues which need to be addressed at state and federal levels.

Walker, D. K. (1988). Educational options for pediatric home care clients. In W. Votroubek & P. McCoy (Eds.), Pediatric home care. Rockville, MD: Aspen.

This chapter discusses current educational options for children with chronic illnesses, including children dependent on medical procedures, regarding eligibility for special education entitlements, types of educational placements and related services available, provision of medical and health services required by the child, and financing of medical and health services in educational settings. The author lays out the steps to be pursued to assure an appropriate education program and the current options.

Walker, P. (1988a). Family supports for children with severe disabilities and chronic illnesses in Maryland. Syracuse, NY: Center on Human Policy.

This is a report of the family supports available for families with children who have severe disabilities and chronic illnesses in Maryland, based on visits to three sites in 1987 and interviews with program staff and visits to families. The report gives brief descriptions of each site. The sites are: the Family Support Services of The Kennedy Institute; the Coordinating Center for Home and Community Care; and SKIP of Maryland. The report discusses key family support issues and practices of each including the family-centered approach, individualized and flexible supports, financial supports, respite, in-home care, social/personal support, case management/service coordination, advocacy, and funding of programs.

Walker, P. (1988b). Home care for children with chronic illnesses: Parents' perspectives. (Unpublished manuscript.) Syracuse, NY: Center on Human Policy.

This is a report of qualitative research using interviews and observation with five families with children who are technology-dependent. The report mainly explores the problems these families face with home care for their children, and also addresses the positive aspects of their experiences. It discusses medical and professional assistance and shortcomings as well as informal supports and the absence of these. The report includes quotes from parents.

Walker, P. (1988c). Where there is a way, there is not always a will: Technology, public policy, and children with chronic illnesses. (Unpublished manuscript.) Syracuse, NY: Center on Human Policy.

This is a brief report on Melissa Detsel, a 9-year old girl with multiple disabilities who receives 24-hour nursing care, paid for by Medicaid. The report was written at a time when she was being denied the opportunity to go to school or elsewhere in the community because of rigid adherence to the language and interpretation of the Medicaid regulation which stipulates that "private duty nursing services" can be provided only in the the recipient's own home or in a hospital or skilled nursing facility. A change in Medicaid regulations is recommended as well as a societal commitment to full integration and inclusion of these children.

Ziegler, M.M. (1988). Fostering home and community-based care for technology-dependent children: Report of the Task Force on Technology Dependent Children (HCFA Publication No. 88-02171). Washington, DC: U.S. Government Printing Office.

This is testimony given before the Task Force by a pediatric surgeon and member of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.). The author describes the work the group has performed in developing standards of care, and also describes the medical characteristics and numbers of children receiving enteral and parenteral nutrition. The author makes recommendations regarding undertaking home care.



**Beach Center on
Families and Disability**

The University of Kansas
Bureau of Child Research
4138 Haworth Hall
Lawrence, Kansas 66045
Tel. (913) 864-7600

Co-Directors: Ann P. Turnbull
and H. Rutherford Turnbull, III